



**American Indian/Alaska Native  
Health Research Advisory Council (HRAC)  
Quarterly Conference Call  
Friday, September 12, 2014**

**HRAC Tribal Delegates and Alternates**

Ileen Sylvester and Jay Butler, MD — Alaska Area Delegate and Alternate  
Aaron Payment — Bemidji Area Delegate  
Christy Duke — Nashville Area (proxy for Dee Sabbatus)  
Tom Anderson — Oklahoma Area Alternate  
Violet Mitchell-Enos — Phoenix Area Alternate  
Michael Percy — National At-Large Member Delegate  
Malia Villegas, PhD — National At-Large Member Alternate

**HRAC Federal Partners**

Kishena C. Wadhwani, PhD — AHRQ  
Adelle Simmons —ASPE  
Chrisp Perry and Gwenivere Rose — HRSA  
Susan Karol, MD, Wilbur Woodis — IHS  
Yvonne Maddox, MD — NIMHD  
J. Nadine Gracia, MD, Rick Haverkate — OMH  
Sheila K. Cooper — SAMHSA

**Other Attendees**

Kendra King Bowes — Native American Management Services, Inc. (NAMS)

**Call to Order and Introductions**

Aaron Payment, HRAC Co-Chair  
Rick Haverkate, Public Health Advisor/American Indian & Alaska Native Health Policy Lead,  
Office of Minority Health (OMH)

- Chairperson Payment and Mr. Haverkate opened the call and welcomed participants. Mr. Haverkate conducted a roll call of tribal delegates and federal representatives.
- Decisions on action items were deferred to the next meeting due to the lack of a quorum.

## **Welcome and HRAC Updates**

Dr. J. Nadine Gracia, MD, MSCE, Deputy Assistant Secretary for Minority Health, U.S. Department of Health and Human Services

- Dr. Gracia opened by thanking Chairperson Payment and Councilman Stephen Kutz for their leadership of the HRAC and their help in moving the priorities forward. In addition, she thanked the HRAC members for their time and dedication providing recommendations to the Department of Health and Human Services.
- Dr. Gracia noted that the HRAC allows the Department to better communicate with tribal communities thereby providing more meaningful insight.
- Dr. Gracia stated that she has been meeting with Mr. Haverkate on a regular basis regarding the HRAC priorities.
- Dr. Gracia noted that she understands that the HRAC Charter is an important part of the HRAC and that there is a workgroup that will review the Charter and make recommendations to OMH. She looks forward to working with the HRAC on the Charter revisions.

## **HRAC Annual Meeting Minutes Approval**

Aaron Payment, HRAC Co-Chair

- Chairperson Payment asked for feedback on the HRAC Annual Meeting Minutes. There were no changes requested and those on the call voted to approve the minutes. However, there was not a quorum so the minutes were not approved.

## **HRAC Updates**

Rick Haverkate, Public Health Advisor/American Indian & Alaska Native Health Policy Lead, Office of Minority Health (OMH)

- Mr. Haverkate stated that he had been meeting with Dr. Gracia on a regular basis. He wanted to inform the group about how dedicated Dr. Gracia and OMH are to the HRAC and AI/AN communities.
- Mr. Haverkate informed the HRAC that OMH reviewed the HRAC priorities and will assist the HRAC in focusing the priorities into something more tangible. He would like to work with the HRAC to develop a logic model to address the HRAC priorities and action items.
- Mr. Haverkate is also working to establish communication strategies for better communications with the HRAC and also so the HRAC can communicate with tribes in their areas about HRAC activities. He asked the HRAC for ideas that would assist with getting information out to the areas and also a way for tribes to respond and provide feedback.

## **HRAC Priorities**

Aaron Payment, HRAC Co-Chair

Rick Haverkate, Public Health Advisor/American Indian & Alaska Native Health Policy Lead, Office of Minority Health (OMH)

- Chairperson Payment reminded the HRAC that there are current priorities and some additional priorities that were recommended during the Research Roundtable. He also stated that he liked the idea of a logic model for identifying tasks and timelines.
- Mr. Haverkate responded to the questions regarding the Research Roundtable recommendations and referred to the email and attachments that were sent out. He noted that the *Potential Priorities Identified* in the HRAC Research Roundtable document were

developed during the Research Roundtable, which was the second day of the June meetings in the Washington, DC Area.

- Chairperson Payment commented that while reading through the priorities he noticed some overlap and suggested incorporating some of the newly recommended priorities into the original document.
- Some members informed Mr. Haverkate that they have been in council meetings and at the National Indian Health Board (NIHB) Conference and have not reviewed the documents as yet. Mr. Haverkate then read through the nine priorities recommended for consideration.
- Dr. Yvonne Maddox noted that NIH is moving quickly to hold an AI/AN Research Symposium with AI/AN investigators. They are bringing together a dozen scientists to discuss the challenges of being a researcher and particularly being an AI/AN researcher. The symposium will likely take place during AI/AN Heritage Month in November. She would like for the HRAC to be represented and invitations will be sent out soon.
- Dr. Maddox reported that she is planning to conduct site visits at some the Tribal Epidemiology Centers (EpiCenters) and asked for suggestions on where she could visit 4 to 5 EpiCenters that are closely located within a three day timeframe.
- Chairperson Payment commented that one of the HRAC priorities is the Native research database/clearinghouse. He noted that he participated in a Tribal Head Start project and from that work realized that there are a lot of efforts/work being done related to studying American Indians and studies conducted by American Indians. He suggested that Dr. Malia Villegas might be able to assist the HRAC. He also commented that the National Congress of American Indians (NCAI) recently brought together Native researchers for a Genetics Symposium and it was very impressive.
- Dr. Maddox commented that she has an extensive list of resumes from Native researchers that she may be able to share soon. She noted that these individuals might be helpful when selecting peer reviewers.
- Dr. Villegas stated that NCAI has a network list of about 2,000 members and NCAI would be happy to help get the information out. She noted that the NCAI Policy Research Center has been sending out quarterly electronic updates, which synthesize early research trends and opportunities. The first one was sent out during the summer and they received a great response. She noted that the HRAC previously mentioned other partner organizations including Tribal EpiCenters and AI/AN research organizations and she suggested the HRAC consider including these organizations in some of the priorities. She stated that the National Science Foundation recently funded a project to help develop AI/AN tenure track positions in the science, technology, engineering, or mathematics (STEM) fields.
- Dr. Maddox commented that the HRAC should consider giving communities credit for work they are doing to advance the numbers of researchers. She also noted that she has been working at NICHD on a definition for health disparities research that will allow those that apply for grants to define their community. She stated that population groups applying for grants are not just minority groups. There are racial/ethnic groups, the underserved, the elderly, communities with disabilities and many more other population groups. She stated that population health is NIH's new initiative and she would like to talk to the AI/AN communities about this initiative.
- Chairperson Payment stated that it sounded like the HRAC has a subcommittee in formation to meet the objective of data collection. He asked Dr. Villegas if she would be willing to

facilitate a process with the partners to pull together the different data points. He commented that he would like to be involved in the process to achieve this goal.

- Dr. Villegas stated that she would be happy to help and indicated that the starting place would be looking at the Westat report from 2007, which is an extensive report on all the existing AI/AN data sets.
- Chairperson Payment asked that members send datasets or lists to Mr. Haverkate's attention. He then returned to the discussion of the Research Roundtable recommendations and HRAC priorities. He noted that the proposed logic model would outline how the HRAC can address the priorities with a timeline. He stated to achieve the goals the HRAC should form a subcommittee to develop the timelines.
- Mr. Haverkate commented that OMH will have an intern this fall and he has proposed to have the intern support the HRAC in the development of logic models. He stated that it would be helpful if the HRAC nominated a few subcommittee members to assist.
- Dr. Villegas also suggested the HRAC develop some one page documents highlighting the HRAC priorities by identifying existing resources and policy recommendations as a way to start moving forward with a broader policy agenda.
- Chairperson Payment commented that he would strongly recommend having the intern work on the logic models to help advance the process. He also recommended that it would be helpful if NIHB could provide technical assistance.
- Ms. Mitchell-Enos asked if there was a quorum on the call. It was confirmed that there was not a quorum. She asked about the call discussions and if it would just be recommendations that the group puts forward for when a quorum can be reached.
- Chairperson Payment stated that in the past notes were taken that identified the recommendations made. Then if a formal vote is needed the items would be held until there is a quorum. He noted that if it was an emergency a vote could be held via phone or email.
- Ms. Mitchell-Enos commented that she did not see some of the priorities that were identified during the HRAC Annual Meeting.
- Mr. Haverkate referred to the HRAC Priorities document dated September 5, 2014. He stated that the other document was titled Potential Priorities Identified at HRAC Research Roundtable.
- Chairperson Payment commended that when looking at research sometimes only the symptoms are looked at. One of the issues that did get embodied in the documents was cultural discontinuity because of historical trauma. The other issue he is beginning to see is undiagnosed learning disabilities and autism. He thinks that there needs to be more effort to better understand the issues. AI/ANs have the highest dropout rate of any population and he thinks there might be a relationship with the environment. He stated this priority could fall under the category of environmental justice, environmental factors or health. He returned the discussion back to the agenda and the HRAC priorities documents. The HRAC priorities document dated September 5 is in a Microsoft Word file with the track changes function utilized to allow HRAC members to see that changes are not made without discussion and everyone can see the evolution of the document. He then asked if there were any other priorities that should be added that were not covered in the documents.
- Dr. Villegas commented that there has been a lot of discussion on genetics data and bio banking including at the symposium that NCAI coordinated in June. She added that the National Human Genome Research Institute just released a data sharing policy that received a good response from Native communities.

- Chairperson Payment commented that at the Centers for Disease Control and Prevention consultation the issue of human samples was discussed including appropriate use and disposal. He noted that one area to be considered is the cultural perspective on this topic.
- Ms. Mitchell-Enos stated that the HRAC did discuss protection of human samples several years back and she doesn't remember if there was mention of having certain allowances or stipulations for Native researchers. In the past it has been primarily non-Native firms looking to do genetic research. She noted the Salt River Pima-Maricopa Tribe has an agreement in place that determines how samples should be handled for research. If federal funding is secured, then the challenge is how that the tribe can keep data. She suggests that the HRAC relook at the issue of human sampling and research and expand this area in the HRAC priorities.
- Ms. Mitchell-Enos informed the HRAC that the Phoenix Area Delegate, Diane Enos, was not reelected.

### **Wrap Up**

- HRAC members should provide any additional feedback to Mr. Haverkate within two weeks.
- Dr. Villegas will be sharing a regional profile for the HRAC to review.

The meeting was adjourned at 4:00 p.m. EDT.